Testimony of Sonja A. Rasmussen, MD, MS

Before the House Select Subcommittee on the Coronavirus Crisis US House of Representatives

Ensuring Scientific Integrity at Our Nation's Public Health Agencies

Friday, April 29, 2022

9:00 a.m.

This testimony reflects my views alone.

Good morning Chairman Clyburn, Ranking Member Scalise, and distinguished members of the committee. Thank you for the invitation to testify on the importance of ensuring the scientific integrity at our nation's public health agencies.

I'm Dr. Sonja Rasmussen, a pediatrician, clinical geneticist, and epidemiologist. For 20 years -- from 1998-2018 -- I worked at the Centers for Disease Control and Prevention. During this time, I served in a variety of leadership roles, in birth defects, infectious diseases, pandemic planning, emergency preparedness and response, and as Editor-in-Chief of CDC's Morbidity and Mortality Weekly Report (MMWR). I am an author on over 270 publications and the lead editor of *The CDC Field Epidemiology Manual*, the guide used by CDC to train Epidemic Intelligence Service officers on how to investigate and respond to acute public health events. I am honored to come before this committee.

Since early 2020 when we first heard reports of a novel coronavirus, I have closely followed the CDC's response to COVID-19. I had served during CDC responses to several public health emergencies including 2009 H1N1 influenza, Ebola virus, and Zika virus – so I knew what my former colleagues were facing. Working on a CDC response to a public health emergency is challenging. The situation is rapidly evolving, and decisions need to be based on limited data. The stakes are high – people are sick and dying -- and the situation is highly visible. Americans want answers now on how to protect themselves and their loved ones from the emerging public health threat.

Developing interim guidance is a difficult process – to weigh the benefits of an intervention against the potential risks, often while the information on which you are basing your decision-making is constantly changing. With a new pathogen like the virus that causes COVID-19, guidance development is particularly difficult. Many questions arise: How is this new pathogen transmitted – droplet or airborne - and how important is transmission from surfaces, can infected persons transmit the virus before they show symptoms, to name a few. You need to consider logistical issues – for example, if you are recommending that people wear masks, are there enough masks available or are they needed for front line health workers who can have an impact on mitigating the pandemic's effects? Feasibility is a critical consideration – thus you obtain input from key stakeholders, people that will be implementing the guidance that you're developing. And then you need to communicate that guidance – and emphasize that it **will change** as additional information becomes available. Fortunately I knew that CDC scientists have the expertise, knowledge, and experience to guide these public health decisions, and are dedicated to maintaining their scientific rigor and integrity throughout the process.

As former MMWR editor-in-chief, I was also closely following MMWR publications. MMWR has long been considered to be the "voice of CDC" with a focus on communicating timely, authoritative, accurate, and objective scientific reports to guide public health action. The publication is well respected, highly cited, and has broad readership in the medical and public health communities. MMWR has served a critical role in providing up-to-date information during previous public health crises. For example, in 1981, cases of what was later known to be AIDS were first reported in the MMWR, which prompted reporting of additional cases and subsequent identification of the disease.

One of the most difficult situations for me to hear about during the pandemic has been reports of political interference with the development of COVID-19 guidelines and demands to review and make changes to MMWR articles. These reports threatened the credibility of CDC and MMWR, essential sources of information to guide us through the pandemic. Watching CDC, an institution that is highly revered around the world, and to which I had dedicated my life's work, lose the trust of many Americans

was painful. And to watch that lack of trust lead to more deaths from COVID-19 has truly been a tragedy.

We know that we will be challenged by future public health threats -- whether another emerging infection, a bioterrorist attack, or a radiation emergency. It is essential that safeguards be put in place to protect the scientific integrity of public health agencies so the American people know they can trust the guidance coming from them. To maintain that trust, these agencies need to be free of political influence. Our ability to protect the health of Americans during future public health threats depends on it.

## **Biography:**

Sonja Rasmussen, MD, MS, is Professor in the Departments of Pediatrics, Obstetrics and Gynecology, and Epidemiology at the University of Florida (UF) College of Medicine and College of Public Health and Health Professions. She serves as a pediatrician and clinical geneticist, seeing a broad range of genetics patients, and as director of UF's Precision Health Program, which focuses on integration of genomics into clinical care. Dr. Rasmussen recently joined UF after 20 years at the CDC in Atlanta. From 1998-20011, Dr. Rasmussen served in the National Center on Birth Defects and Development Disabilities, where she worked on a large case-control study to identify genetic and environmental risk factors for birth defects, and on studies to better understand the morbidity and mortality associated with several genetic conditions. From 2011-2014, she served as Deputy Director of the Influenza Coordination Unit, responsible for CDC's pandemic influenza preparedness, and for 6 months, served as the Acting Director of the Office of Public Health Preparedness and Response, responsible for CDC's public health preparedness and response activities. From 2015-2018, she served as Editor-in-Chief of CDC's Morbidity and Mortality Weekly Report (MMWR) Series and as the Director of the Division of Public Health Information Dissemination. Dr. Rasmussen was lead author of the paper confirming Zika virus as a cause of birth defects, published in the New England Journal of Medicine in 2016. She served in leadership roles during several CDC responses to public health emergencies, including 2009 H1N1 influenza, H7N9 influenza, Middle East Respiratory Syndrome (MERS) coronavirus, Ebola, and Zika virus.

Dr. Rasmussen is an author on >270 papers in the peer-reviewed literature and is the lead editor of *The CDC Field Epidemiology Manual*, published by Oxford University Press in 2018. She is board-certified in Genetic Counseling, Pediatrics, and Clinical Genetics.

## **Relevant citations:**

Protecting the Editorial Independence of the CDC From Politics. Rasmussen SA, Ward JW, Goodman RA. JAMA. 2020 Nov 3;324(17):1729-1730. doi: 10.1001/jama.2020.19646. PMID: 32960274

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### VIEWPOINT

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Beginning September 11, 2020, media sources reported that political appointees within the US Department of Health and Human Services (HHS) have demanded the ability to review and revise scientific reports on the coronavirus disease 2019 (COVID-19) pandemic published in Morbidity and Mortality Weekly Report (MMWR), published by the Centers for Disease Control and Prevention (CDC).<sup>1,2</sup> According to these sources, reviews by political appointees have sometimes led to delays in publication and changes in language in certain reports. Whether this is true is unclear, but these reports are consistent with other reports of the actions of political appointees and their attempts to influence the scientific process.<sup>3</sup> As former editors in chief of MMWR, we believe these media reports raise serious concerns that in the midst of the COVID-19 pandemic, scientific reports published in MMWR might have been delayed or altered for political purposes. These concerns threaten the credibility of MMWR, an essential source of information to help counteract the pandemic.

From Politics

Protecting the Editorial Independence of the CDC

Since 1961, when CDC began publishing *MMWR*, the publication has been considered to be the "voice of CDC," with a focus on communicating timely, authoritative, accurate, and objective scientific reports to guide

# Now more than ever, it is imperative to ensure that the public's trust in *MMWR* as the voice of CDC is maintained.

public health action. The publication has broad readership including public health practitioners, epidemiologists, physicians and other health care professionals, other scientists, educators, and laboratory workers, among others. MMWR reports are also closely followed and amplified by the news media. In addition to reports published weekly, CDC releases MMWR reports on an urgent basis for immediate dissemination of information on disease outbreaks and other health threats. MMWR also publishes comprehensive articles that delineate CDC science-based recommendations for prevention and treatment, including recommendations from the Advisory Committee on Immunization Practices (ACIP), an external federal advisory committee of experts that provides recommendations to CDC regarding vaccines.

As with all scientific manuscripts authored by CDC professionals or published by CDC, submissions to *MMWR* undergo a rigorous internal peer review clearance process by epidemiologists, laboratorians, and other technical experts.<sup>4</sup> The goal of this process is to ensure that the content incorporates relevant input from

experts across the agency and is scientifically valid and technically accurate.<sup>5</sup> The extent of this internal review process depends on the range of issues covered, the complexity of the science, and the potential effects of the findings. Typically this process takes about 4 weeks,<sup>5</sup> although it is expedited when urgent release of a report is needed.

MMWR serves a critical role in providing up-todate information during the COVID-19 pandemic. This is consistent with the role it has had during previous public health crises.<sup>6</sup> For example, in 1981, a report of 5 cases of Pneumocystis carinii (now P jiroveci) pneumonia among previously healthy young men in Los Angeles was published in MMWR, which prompted reporting of additional cases and subsequent identification of AIDS. In 2001, following intentional exposures to anthrax sent through the mail, MMWR was used to update health care clinicians and organizations, public health professionals, and the public regarding the investigation and guidelines for clinical diagnosis and management. In 2003, when the virus causing severe acute respiratory syndrome (SARS) emerged and spread throughout the world, MMWR published reports that alerted the nation to the course of the epidemic, clinical manifesta-

> tions, diagnostic testing, and methods to prevent transmission.<sup>6</sup> During 2016-2018, *MMWR* reported the emergence of the Zika epidemic in the Americas with guidance for obstetricians and pediatricians for care of Zika-exposed pregnant women and their infants.<sup>7</sup>

*MMWR* is highly cited in the medical literature: in 2019, *MMWR* weekly had the highest number of citations of any journal in the epidemiology category, according to Google Scholar, and the *MMWR* series has a 2019 journal impact factor of 13.6. In addition, commentaries on *MMWR* articles of prime interest are often published in leading journals.<sup>8</sup>

Large disease outbreaks usually generate high levels of public concern, including among elected officials and their staff. Thus, HHS and others in the executive branch frequently have a keen interest in *MMWR* articles. Many controversial and sensitive issues have been published in *MMWR*, including HIV, anthrax, SARS, Ebola, and Zika. To address the administration's interest at the time of those publications, CDC has shared the topics of upcoming reports with health officials in HHS; however, the actual reports were not reviewed or shared outside of CDC. During the 20 years of collective experience of the authors of this Viewpoint and spanning 5 presidential administrations, CDC leadership maintained a stringent firewall to ensure *MMWR* editorial independence and to guard against political interfer-

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ence. Decisions about what to publish and when were based on the science and public health needs. Thus, while the science of public health is essential for informing decisions of elected officials, it has long been recognized that for the scientific reports of *MMWR* to be respected and trusted, they must be free of political influence.

Whether the allegations regarding political appointees delaying or altering MMWR articles are true is unknown. However, even the perception that MMWR reports could be delayed or altered for political purposes is damaging to the reputation of CDC. These allegations could undermine the confidence of readers in the scientific integrity of MMWR reports that are relied on by large audiences in the US and globally. At a time when the scientific integrity in government health agencies has been questioned,<sup>3</sup> MMWR needs to remain a trusted venue for publication. Preservation of MMWR as an essential source of information for public health action has important implications for the COVID-19 epidemic. Once COVID-19 vaccines are licensed by the US Food and Drug Administration (FDA), official recommendations for their use developed by the ACIP are expected to be published in MMWR, as they were during the 2009 H1N1 influenza pandemic.<sup>9</sup> Any perception that these recommendations are inappropriately influenced by political considerations—or any other considerations aside from scientific evidence—could hinder delivery of COVID-19 vaccines by clinicians and acceptance of vaccines by the public.

To address the COVID-19 epidemic and other threats to the nation's health, prompt action is needed. First, HHS leadership, not just CDC staff, needs to affirm its commitment to preserving the integrity of CDC science, including publications in *MMWR*. Second, CDC leadership can review and, when indicated, strengthen measures for ensuring the editorial independence of *MMWR* to prevent future political interference. Third, the *MMWR* editorial board, a highly respected group of experts in medicine and public health, can assist in these efforts by reviewing these measures and advising additional options to ensure the continued quality and scientific integrity of *MMWR*.

The COVID-19 pandemic has placed great demands on local, state, and federal public health officials and on health care systems. Health professionals and the public they serve deserve information from CDC based on the best available science. For nearly 60 years, *MMWR* has served as a trusted source of public health information. Now more than ever, it is imperative to ensure that the public's trust in *MMWR* as the voice of CDC is maintained.

### ARTICLE INFORMATION

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**Disclaimer:** The views expressed in this article are those of the authors and do not necessarily represent those of any institutions with which they are currently or have been formerly affiliated.

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Additional Information: The authors served as editors in chief of *MMWR*: Dr Rasmussen from 2015 to 2018, Dr Ward from 1998 to 2005, and Dr Goodman from 1988 to 1998.

#### REFERENCES

 Diamond D. Trump officials interfered with CDC reports on Covid-19. *Politico*. Published September 11, 2020. Accessed September 15, 2020. https:// www.politico.com/news/2020/09/11/exclusivetrump-officials-interfered-with-cdc-reports-oncovid-19-412809

2. Schultz M. Trump aides review CDC coronavirus reports to better align with president's upbeat messaging: report. *Fox News*. Published September 13, 2020. Accessed September 15, 2020. https://www.foxnews.com/politics/trump-aides-review-cdc-coronavirus-reports-to-better-align-with-presidents-messaging-report

3. Goodman JL, Borio L. Finding effective treatments for COVID-19: scientific integrity and public confidence in a time of crisis. *JAMA*. 2020; 323(19):1899-1900. doi:10.1001/jama.2020.6434

 CDC. Morbidity and Mortality Weekly Report (MMWR) Recommendations and Reports/ Surveillance Summaries Instructions for authors. Updated November 8, 2018. Accessed September 16, 2020. https://www.cdc.gov/mmwr/author\_ guide\_rrss.html 5. Cono J, Jaffe H. The CDC clearance process: supporting quality science. *Am J Public Health*. 2015;105(6):e1-e2. doi:10.2105/AJPH.2015.302691

 Shaw FE, Goodman RA, Lindegren ML, Ward JW; Centers for Disease Control and Prevention (CDC).
A history of MMWR. MMWR Suppl. 2011;60(4):7-14.

7. CDC. *MMWR* Zika reports. Updated July 17, 2020. Accessed September 15, 2020. https://www. cdc.gov/mmwr/zika\_reports.html

8. Grohskopf LA, Liburd LC, Redfield RR. Addressing influenza vaccination disparities during the COVID-19 pandemic. *JAMA*. 2020;324(11):1029-1030. doi:10.1001/jama.2020.15845

 National Center for Immunization and Respiratory Diseases, Centers for Disease Control and Prevention (CDC). Use of influenza A (H1N1) 2009 monovalent vaccine: recommendations of the Advisory Committee on Immunization Practices (ACIP), 2009. MMWR Recomm Rep. 2009;58(RR-10):1-8.

# Public Health Decision Making during Covid-19 — Fulfilling the CDC Pledge to the American People

Sonja A. Rasmussen, M.D., and Denise J. Jamieson, M.D., M.P.H.

n May 2020, the Centers for Disease Control and Prevention (CDC) released considerations for the opening of elementary and high schools in the fall in light of the Covid-19 pandemic. The agency also developed a decision tool to guide school systems in deciding when schools should be opened and a 9-page checklist for school administrators with policies and procedures, facilities and supplies, and education and training needed for safe reopening of schools. The day after a July 7 meeting at the White House to discuss school reopening with school system administrators, teachers, and students, President Donald Trump expressed concern about the practicality of the guidelines and the expenses associated with following them; later that day, Vice President Mike Pence announced that the CDC would be revising the guidelines. The next day, the CDC director clarified that the guidelines would not be revised, but that additional reference documents would be provided to aid communities as they worked to implement the guidelines. On July 23, the CDC released additional documents emphasizing the critical role of schools and the importance of opening them for in-person instruction. This interchange among federal leaders raises concern that during the response to the most critical public health emergency of our lifetimes, guidelines regarding the safety of schoolchildren in the United States could

be based not on the best scientific data available, but on political considerations.

It is hard to imagine a more important issue than the safety of our country's schoolchildren during a pandemic. As is often the case with an emerging infection, the data needed to make policy decisions about school reopening are incomplete. The many benefits of in-person learning for children are clear and include not only academic progress, but also positive effects on social and emotional skills and mental health and the provision of nutritional services. In addition, in-person learning for children allows parents to return to their work activities.

However, data on the risks that school reopening poses for children, teachers, and their communities remain limited. Children appear to be less likely to become infected with SARS-CoV-2, the virus that causes Covid-19; of 149,082 U.S. cases reported between February 12 and April 2, 2020, only 2572 (1.7%) were in children younger than 18,1 although the possibility that some children are infected but asymptomatic, and therefore not tested, cannot be excluded. Available data suggest that children are at low risk for severe disease or death,<sup>1</sup> but children with underlying conditions, including immune suppression, cancer, obesity, or diabetes, have been shown to be at increased risk for severe disease necessitating admission to an intensive care unit.<sup>2</sup> The recent emergence of the multisystem inflammatory syndrome in children (MIS-C), a severe and life-threatening illness, raises additional concerns. MIS-C appears to be a rare event following infection with SARS-CoV-2; however, in a recent study, three quarters of children with MIS-C had no documented underlying conditions, so predicting which children might develop this complication is not currently possible.<sup>3</sup>

Although most children infected with SARS-CoV-2 are mildly affected, the same cannot be said for the teachers, parents, grandparents, and others who will be exposed to potentially infected children. At this time, data on transmission of SARS-CoV-2 from infected children are limited. A recent report on contact tracing from South Korea, however, sheds light on this issue: household contacts of children 10 to 19 years of age had the highest rate of Covid-19 (18.6% tested positive, as compared with 11.8% of contacts of infected persons of all ages), while contacts of children 0 to 9 years of age had the lowest rate (5.3% tested positive).<sup>4</sup> Rates of infection among nonhousehold contacts were low, but the study was done at a time when schools were closed, which limited the opportunity for transmission from children to people outside their households. The effects of school reopening on transmission of Covid-19 in communities are also

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not well understood. The value of school closures in reducing the spread of seasonal and pandemic influenza has been demonstrated, but whether these findings apply to Covid-19 is unknown.<sup>5</sup>

When faced with a decision of such gravity, it is essential that experts in epidemiology, public health, pediatrics, and infectious disease, in consultation with eduneed to be made. Maintaining Americans' confidence in public health leaders is essential to an effective response not only to Covid-19, but to other public health emergencies that the country may face in the future.

During the Covid-19 response, the greatest challenge to public health in more than 100 years, science must guide public health

Maintaining Americans' confidence in public health leaders is essential to an effective response not only to Covid-19, but to other public health emergencies that the country may face in the future.

cators and members of affected communities and institutions, lead the efforts to develop guidelines that are based on the best scientific data available. As the American Academy of Pediatrics, the American Federation of Teachers, and other national organizations noted in a press release on July 10, "Returning to school is important for the healthy development and well-being of children, but we must pursue reopening in a way that is safe for all students, teachers and staff. Science should drive decision making on safely reopening schools."

Longer-term concerns about undermining public confidence in public health decision makers also need to be considered. Although the current pandemic disrupted the daily lives of Americans in ways not seen since the 1918 influenza pandemic, one can imagine future emergencies (e.g., a bioterrorist attack or radiation emergency) in which even more rapid and drastic decisions may decision making. As former CDC employees with more than 40 years' combined experience, which included playing leadership roles in the CDC responses to the 2009 H1N1 influenza epidemic and the Ebola and Zika emergencies, we recognize that these decisions made in the midst of a public health emergency are fraught with challenges and require careful consideration of the risks and benefits of various options. Available data must be rapidly analyzed and interpreted, even when key data necessary to guide decision making are incomplete or unavailable. Existing evidence as well as critical gaps in knowledge need to be carefully documented. These decisions are often guided by modeling efforts and by individual input from professional organizations and community members. As additional information becomes available, guidance needs to be adapted to incorporate the new knowledge.

CDC scientists have the exper-

tise, knowledge, and experience to guide these public health decisions, as evidenced by the multiple sets of guidelines produced during responses to past emergencies. Decisions made during the H1N1, Ebola, and Zika epidemics were highly visible, often leading the news, and the CDC's responses were subject to substantial scrutiny. Yet the agency maintained its scientific rigor and integrity in developing guidelines.

As we consider these recent events, we are reminded of the CDC's Pledge to the American People. This pledge, available on the CDC website, appeared on a large wall that we passed daily while working on emergencyresponse activities. The pledge states that CDC employees should "base all public health decisions on the highest quality scientific data that is derived openly and objectively." Current CDC employees must be allowed to fulfill their pledge: our country's ability to succeed in the fight against the Covid-19 pandemic depends on it.

The views expressed in this article are those of the authors and do not necessarily represent those of any institutions they are or previously have been affiliated with.

Disclosure forms provided by the authors are available at NEJM.org.

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1. CDC COVID-19 Response Team. Coronavirus disease 2019 in Children — United States, February 12–April 2, 2020. MMWR Morb Mortal Wkly Rep 2020;69:422-6.

2. Shekerdemian LS, Mahmood NR, Wolfe

N ENGL J MED 383;10 NEJM.ORG SEPTEMBER 3, 2020

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KK, et al. Characteristics and outcomes of children with coronavirus disease 2019 (COVID-19) infection admitted to US and Canadian pediatric intensive care units. JAMA Pediatr 2020 May 11 (Epub ahead of print).

3. Feldstein LR, Rose EB, Horwitz SM, et al.

Multisystem inflammatory syndrome in U.S. children and adolescents. N Engl J Med 2020; 383:334-46.

**4.** Park YJ, Choe YJ, Park O, et al. Contact tracing during coronavirus disease outbreak, South Korea, 2020. Emerging Infect Dis 2020 July 16 (Epub ahead of print).

5. Esposito S, Principi N. School closure during the coronavirus disease 2019 (COVID-19) pandemic: an effective intervention at the global level? JAMA Pediatr 2020 May 13 (Epub ahead of print).

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# Long-Term Care Policy after Covid-19 — Solving the Nursing Home Crisis

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Nursing homes have been caught in the crosshairs of the coronavirus pandemic. As of early May 2020, Covid-19 had claimed the lives of more than 28,000 nursing home residents and staff in the United States.<sup>1</sup> But U.S. nursing homes were unstable even before Covid-19 hit. They were like tinderboxes, ready to go up in flames with just a spark. The tragedy unfolding in nursing homes is the result of decades of neglect of long-term care policy.

Since the U.S. coronavirus outbreak began in a nursing home in Kirkland, Washington, more than 153,000 residents and employees of 7700 U.S. nursing homes have contracted Covid-19, accounting for 35% of the country's deaths.1 Here, as in many other countries, nursing homes have been ill equipped to stop the spread of the virus. They lacked the resources necessary to contain the outbreak, including tests and personal protective equipment, and their staff are routinely underpaid and undertrained. Furthermore, nursing homes were sitting ducks for Covid-19, housing people who are particularly vulnerable to poor outcomes of the virus, often in shared living quarters and communal spaces, making social distancing or isolation difficult, if not impossible.

But this crisis in nursing homes is not a new problem. Long-term care in the United States has been marginalized for decades, leaving aging adults who can no longer care for themselves at home reliant on poorly funded and insufficiently monitored institutions. Although major regulatory policies, including the Federal Nursing Home Reform Act of 1987, have attempted to address deficiencies in the quality of care, Covid-19 has highlighted the fact that better monitoring is not enough. The coronavirus has exposed and amplified a longstanding and larger problem: our failure to value and invest in a safe and effective long-term care system.

Indeed, long-term care has been sidelined in our federal social welfare policies since the 1960s, when Medicare and Medicaid created narrow and incomplete social insurance programs for such care. These programs adopted a medicalized model of care, prioritizing the use of licensed providers and institutions. This model made nursing homes the default provider of long-term care and made the care provided by families and others outside these licensed facilities invisible, leaving it unsupported.

Furthermore, Medicare and Medicaid were never intended to pay for the lion's share of longterm care. Medicare funds longterm care only temporarily and tangentially by covering nursing home–based rehabilitation after a hospital discharge. Medicaid finances more than half of all long-term care for people who need help with daily activities, such as bathing, dressing, or eating, but it's available only to people who have spent down their own assets, and it has coverage gaps.

And financing of nursing home care by both Medicare and Medicaid has been declining. Nursing homes have seen decreasing occupancy for decades, despite the aging of the U.S. population. The number of patients discharged from the hospital to a nursing home for rehabilitation has also declined.<sup>2</sup> In an effort to constrain health care spending, these patients are being sent directly home, which puts the squeeze on a critical part of nursing homes' revenue. Since the pandemic began, short stays have all but vanished, as nursing homes turn away patients after hospital

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